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COPING WITH METASTATIC MELANOMA: THE LAST YEAR OF LIFE

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SUMMARY

Background: Few longitudinal studies have concurrently investigated cognitive appraisal, coping and psychological adjustment in patients with terminal cancer. This study aimed to (i) consider patterns of change in these variables during the last year of life and (ii) consider covariates associated with patients' psychological adjustment.

Methods and patients: Questionnaires were sent to a cohort of stage IV melanoma patients seen at the Sydney Melanoma Unit between 1991 and 1996, approximately every 3 months, for up to 2 years. A sub-sample of 110 patients completed at least one questionnaire in the last year of life. Repeated measures linear regression was used to model cognitive appraisal, coping and psychological adjustment.

Results: In the last year of life, patients' cognitive appraisal of their disease remained relatively stable, whereas their use of active coping strategies increased ($p = 0.04$). There was some deterioration in psychological adjustment, particularly in patients' ability to minimize the impact of cancer on daily life ($p = 0.03$), but this effect did not remain significant when patients' level of tiredness was included in the model. Cognitive appraisal, coping style and quality of life indicators were all associated with psychological adjustment.

Conclusion: These findings suggest that while patients work hard to actively cope with their disease, they experience increasing levels of tiredness, and deterioration in their mood and ability to function in their daily lives.

INTRODUCTION

The psychosocial demands that confront cancer patients vary over the course of the illness (Dean and Surtees, 1989; Buddeberg *et al*., 1996; Schain, 1976). The time of diagnosis is described as being particularly distressing (Weisman, 1972; Manuel *et al*., 1987; Edgar *et al*., 1992) and has attracted much attention with respect to understanding patterns of coping and psychological adjustment (Carver *et al*., 1993). However, few studies have considered the relationships between these variables in patients with terminal disease. Thus, in this paper we will consider patients' psychological experiences specifically in the last year of life.

The way in which patients adjust to their illness is shaped substantially by their reaction to events (cognitive appraisal) and their capacity to cope with emerging problems. For example, feeling threatened or concerned about how their illness may impact upon specific life areas is associated with poorer adjustment (Stanton and Snider, 1993). Likewise, use of an avoidant coping style (or denial) has been associated with higher levels of distress and poorer psychological adjustment in early stage breast cancer patients (Dunkel-Schetter *et al*., 1992; Carver *et al*., 1993; Stanton and Snider, 1993; McCaul *et al*., 1999).

Psychosocial adjustment and coping style are also correlated with certain disease and patient characteristics such as age. For example, coping style appears to mediate the effects of age and stage of illness on psychological adjustment (Dunkel-Schetter *et al*., 1992; Schnoll *et al*., 1998). Stanton and Snider (1993) and McCaul *et al*. (1999) found that older patients reported better

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psychological adjustment. However, in the example of Stanton and Snider (1993), age was significant only when considered simultaneously with variables measuring cognitive appraisal and coping style. Physical symptoms have also been found to exert a negative impact on psychological adjustment (Ell *et al.*, 1989), although this analysis did not simultaneously include measures of cognitive appraisal or coping.

Coping style also varies over the course of the illness, and is correlated with changes in psychosocial demand (Heim *et al.*, 1997). Lazarus and Folkman (1984) identify two broad types of coping, emotion-focused and problem-focused. Emotion-focused strategies reduce emotional distress when the person appraises the situation as being beyond their control. On the other hand, problem-focused strategies focus on problem solving and are more likely to be used when the situation is appraised as being within the subject's control (Folkman *et al.*, 1986). It could be argued that emotion-focused coping strategies (e.g. avoidance, denial and distraction) are more likely to be used at diagnosis when the patient is feeling overwhelmed, or near death when it becomes apparent that nothing more can be done. Likewise problem-focused strategies (e.g. learning more about the disease) may be used in the intervening period when patients are more likely to be able to positively reframe the situation.

Few long-term studies have concurrently investigated patterns of change over time in patients' cognitive appraisal, coping and adjustment in the terminal illness phase. Thus, one of the aims of this study was to explore patterns of change in these variables during the last 12 months of life for patients with metastatic melanoma. We chose to focus on the last 12 months of life since this is a period of increasing stress for patients, carers and their families. We were also interested in examining associations between psychological adjustment and a range of covariates including patient characteristics, disease variables, cognitive appraisal, coping style and physical symptoms.

Specifically, during the study period, we hypothesized that: (1) patients' cognitive appraisal of their situation, as reflected by patient worries/concerns, would increase over time; (2) patients would move from using problem-focused to emotion-focused coping strategies; (3) psychological adjustment would deteriorate as death approached; (4) that older patients would report better adjustment; (5) that high levels of threat would be associated with poorer psychological adjustment; and (6) use of avoidant coping strategies would be associated with poorer adjustment.

PATIENTS AND METHODS

The study population consisted of patients seen at the Sydney Melanoma Unit between 1991 and 1996 who participated in a larger study exploring psychosocial predictors of outcome. Response rates to chemotherapy in these patients are generally below 30% (Coates, 1992; Aapro, 1993), and once the disease has spread, median survival is less than 1 year (Coates and Durant, 1985; Vijuk and Coates, 1998). Exclusion criteria included an inability to speak English fluently, co-existing psychiatric illness and extreme morbidity that would prevent patients from completing questionnaires.

Participating patients were asked to complete a series of questionnaires that were repeated every 3 months, where possible, for up to 2 years. Disease and demographic data were obtained from medical records. At the close of the study, disease status and outcome were determined through a search of computerised and paper-based medical records and, where necessary, by contact with the patient's general practitioner. Patients who had completed one or more questionnaires in the last year of life were selected as a sub-sample for this analysis. This included patients who already had distant metastases at study entry and those patients whose disease metastasized while participating in the study.

Psychosocial assessment

Measures employed represent an attempt to systematically obtain data on the range of significant psychosocial factors thought to be associated with human responses to illness, using measures with proven psychometric status and applicability to cancer populations. These measures were grouped together into three 'families' of variables measuring cognitive appraisal, coping and psychological adjustment.

Cognitive appraisal of threat: independence, family and disease. Cognitive appraisal is the process by which a person evaluates the threat implicit in a stressful encounter. We used the 13-item cognitive appraisal subscale of the Stress Questionnaire

(Folkman *et al.*, 1986). Each item has a 5-point Likert scale from 'worries me all the time' to 'does not worry me at all'. Factor analysis in this sample yielded three factors concerning independence, family and disease with Cronbach alphas of 0.80, 0.80 and 0.68, respectively. Concerns about independence included six items such as 'I will not be able to work'. Concerns about family included three items such as 'my family will be upset'. Concerns about disease included four items such as 'I will have to cope with a lot of pain'. Items were summed to a factor score and were linearly transformed to a scale of 0 to 100, with high scores indicating a great deal of concern/distress.

Patients were defined as being very concerned if their scores exceeded 75.

The value of 75 was selected in order to identify those patients with high to very high concerns. Scores over 75 indicated that on average, patients reported either agreement or strong agreement with the negative items within each factor and disagreement and or strong disagreement with positive items.

Coping: active, distraction and avoidant. Coping is the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of a person. We used a self-report adaptation of the Weisman and Wordon General Coping Strategies Scale, the COPE, which measures the frequency of use of 15 problem-solving and emotion-focused coping strategies (Weisman and Worden, 1976). The COPE has been used successfully with cancer patients, and has been shown to be sensitive to age, diagnosis and staging of the illness. Patients indicated on a 5-point Likert scale the frequency with which they used each coping style (never to always). Factor analysis of the COPE in this sample yielded three factors: active, distraction and avoidant coping. Cronbach alphas for the three factors were 0.72, 0.52 and 0.30, respectively. The avoidant and distraction factors contained emotion-focused strategies while the active coping factor contained problem-focused strategies. Items were summed then linearly transformed to a scale of 0–100, with a high score indicating frequent use of that coping style. Active coping included three items such as 'seeking more information about the situation' and 'doing anything I can do, such as meditation'. Distraction coping included five items such as 'trying to forget, putting it out of my mind', and 'living life with a new intensity, doing everything I've been meaning to do'. Avoidant coping included four items such as 'drinking, eating or taking drugs to feel less tense', and 'being on my own a lot, keeping the feelings inside'.

Psychological adjustment: isolation, minimization and anger. Psychological adjustment is defined as the functional outcome of coping, including maintenance of emotional equilibrium, acceptance of the illness and maintenance of positive self-esteem. Psychological adjustment was measured using the 53-item Psychological Adjustment to Cancer (PAC) scale (Dunn *et al.*, 1997). The sensitivity of the PAC has been demonstrated in a randomized controlled trial assessing the impact of the use of the word 'cancer' and euphemisms for it (Dunn *et al.*, 1993). Patients indicated on a 5-point Likert scale the degree to which they agreed or disagreed with each statement. A factor analysis in this sample resulted in the adaptation of the scale to a shorter 24-item, 3-factor scale, measuring stigma/isolation, minimization and anger, with Cronbach alphas of 0.81, 0.65 and 0.69, respectively. Items were summed, then linearly transformed to a scale of 0–100. High scores indicate greater levels of isolation, minimization and anger. The stigma/isolation factor included 14 items such as 'I try not to let people know about my cancer' and 'since getting cancer my body has felt unclean'. The minimization factor included seven items such as 'having cancer is not making any difference to my life at all' and 'the thought of having treatment does not worry me'. The anger factor included nine items such as 'cancer is the worst thing that has ever happened to me' and 'I am constantly asking myself the question—why me?'.

Disease and demographic variables

The following demographic and disease variables were recorded: age, gender, marital status, survival time (time since diagnosis of distant metastases), site of metastases, and whether patients had received treatment at the time of completing the questionnaire.

Quality of Life (QOL) indicators

Physical indicators of QOL were assessed using four single-item linear analogue self-assessment (LASA) scales. The LASA scales were scored from 0 to 100 using a line 100 mm long. Each scale is anchored at either end by phrases representing the extremes of experience with a higher score reflecting better indicator of QOL. Two scales were taken from the GLQ8 (Coates *et al.*, 1990): feeling sick and tiredness. These were anchored by 'none' and 'worst I can imagine'. Two other QOL indicators (Coates *et al.*, 1983) were also used: physical well-being (anchored by 'lousy' and 'good') and appetite (anchored by 'none' and 'good'). These scales have been shown to have adequate reliability and validity (Butow *et al.*, 1991; Hurny *et al.*, 1993; Bernhard *et al.*, 1997).

Statistical analysis

Patterns of change over time. In order to test our hypotheses, repeated measures linear regression was used to model cognitive appraisal, coping and psychological adjustment using MLwiN version 1.02 (Goldstein, 1995). Such models, also known as multilevel or hierarchical models, consider repeated observations (level 1) to be 'nested' within patients (level 2). This approach is useful for data with differing numbers of observations per patient and no fixed time points. Time was centred on each individual's own average time, such that each person's intercept represented their own average score for each variable considered.

For each of the analyses, fixed effect (slope) was tested using the ratio of the estimate to its standard error, which has a 't' distribution with degrees of freedom equal to 'n' patients—1 (Bryk and Raudenbush, 1992). The significance level α was set at 0.05.

Covariates of psychological adjustment. In order to explain differences between patients' level of psychological adjustment, covariates were added as fixed effects to the linear regression models. Covariates included demographic, disease and QOL indicator variables and two families of psychosocial variables (i.e. coping styles and cognitive appraisal). Each covariate was considered both on its own (univariate) and together with the other variables in its family. Variables found to have a significant association with psychological adjustment were included in a multivariate model. Demographic and disease variables that have been reported in the literature as important, but were not significant in univariate analyses, were then tested within the multivariate model. This was to ensure that potential confounders were fully considered. Only significant variables were included in the final model. The statistical significance of each covariate was tested with the ratio of its estimate to its standard error (S.E.), which has 't' distribution with degrees of freedom equal to 'n' patients $-$ s level 2 predictors $-$ 1 (Bryk and Raudenbush, 1992). The significance level α was set at 0.05 for each covariate.

RESULTS

Selection of sub-sample

Only those patients who died and had completed at least one questionnaire in the last year of life were included in the analysis, leaving a final sample of 110 patients with 190 observations. That is, the sample included 91 of the 125 patients who entered the study with distant metastases, and a further 19 of 505 patients with primary melanoma whose disease had progressed during the study. Fifty-four percent of the sample completed one questionnaire, 26% completed two, 13% completed three and 7% completed four questionnaires. Thirty-seven percent of patients completed their final questionnaire within 2 months of death. Demographic and disease characteristics of the patients are shown in Table 1.

Comparison between respondents and non-respondents

For the purposes of this study, non-respondents were defined as patients who potentially could have completed questionnaires in their last year of life had they entered the study. In total, 95 patients met this criteria with 89 having distant metastases at the time they were invited to join the study. Respondents and non-respondents did not differ on age ($t = 0.31$, $p = 0.755$), marital status ($\chi^2_3 = 3.81$, $p = 0.284$) or site of metastasis ($\chi^2_4 = 2.17$, $p = 0.704$). However, women were more likely than men to participate in the study ($\chi^2_1 = 4.52$, $p = 0.03$) and non-respondents were closer to death at the time they were invited to

Table 1. Demographic and disease characteristics of the sample ($n = 110$)

	Mean (S.D.)
Age (years)	55 (15)
Survival (time (months) since diagnosis of distant metastases)	6 (8)
	%
Gender	
Male	68
Female	32
Education	
Primary	3
Intermediate	53
HSC	11
Technical	13
Undergraduate/postgraduate	20
Occupation	
Managers/administrators/professionals	43
Tradespersons	16
Sales/personnel/clerks	26
Machine operators/labourers	15
Ethnicity	
Australian	90
Non-Australian	10
Marital status	
Single	8
Married/*de facto*	77
Separated/divorced	5
Widowed	10
Metastatic site	
Non-visceral	10
Bone	3
Other-visceral (other than liver or brain)	38
Liver	28
Brain	21

join the study (Logrank = 16.10, $p < 0.001$). Median survival time for respondents and non-respondents was 8.5 and 4.5 months, respectively. This suggests that those patients who were sickest at the time of recruitment did not participate in the study.

Patterns of change in the last year of life

Patterns of change over time for each of the variables measuring cognitive appraisal, coping style and psychological adjustment were modelled. Results are presented in Table 2.

Patterns of cognitive appraisal (concerns). For concerns about independence, disease and family there were no significant time effects (slopes), indicating that on average there was little net change over the last year of life. Thus, the hypothesis that patients' cognitive appraisal of their situation would change over time, was not supported. The group means (intercepts) in Table 2 suggest that patients reported more concern about their family than about either their independence or disease. Indeed 16% of patients expressed a high level of concern in this area, compared with 0% of patients expressing a high level of concern regarding independence and 2% for disease.

Patterns of coping style. Patients' use of active coping significantly increased over the final year of life ($t = 0.029/0.014$, $p = 0.041$). Thus, the hypothesis that patients would move from problem-focused (active) to emotion-focused coping strategies over time, was not supported. Rather, the use of problem-focused strategies increased over the last year of life, whereas the frequency of use of emotion-focused coping strategies (i.e. distraction/avoidance) did not change ($p > 0.05$).

Patterns of psychological adjustment. Patients' experiences of isolation and anger increased in the last year of life but this increase only approached significance (isolation: $t = 0.0.017/0.009$, $p = 0.062$; anger: $t = 0.021/0.012$, $p = 0.083$). As death approached, patients also found it harder to minimize the impact of their cancer on day-to-day life (minimization: $t = -0.022/0.010$, $p = 0.03$).

Variables associated with psychological adjustment

Variables that accounted for differences in the mean level of isolation, minimization and anger were considered, and are presented in Table 3. None of the demographic or disease variables were associated with these outcomes. Cognitive appraisal was positively associated with feelings of isolation and anger and negatively associated with patients' ability to minimize the impact of their cancer. All four indicators of QOL were positively associated with patients' ability to minimize the impact of their cancer and negatively associated with feelings of isolation and anger. For example, a patient who minimized the impact their cancer, and expressed low levels of anger was likely to

Table 2. Patterns of change over time for cognitive appraisal, coping style and psychological adjustment

	Intercept	Slope (S.E.)	*p*-value (slope)
Cognitive appraisal			
Independence	29.1 (1.8)	0.005 (0.012)	0.68
Family	45.5 (2.3)	−0.003 (0.018)	0.87
Disease	28.8 (1.7)	−0.003 (0.012)	0.80
Coping style			
Active	56.2 (1.9)	0.029 (0.014)	0.04
Distraction	37.8 (1.6)	0.016 (0.010)	0.11
Avoidance	55.7 (1.5)	−0.012 (0.010)	0.23
Psychological adjustment			
Isolation	29.2 (1.1)	0.017 (0.009)	0.06
Minimization	48.3 (1.3)	−0.022 (0.010)	0.03
Anger	52.5 (1.4)	0.021 (0.012)	0.08

Table 3. Associations between demographic, disease, QOL indicators and psychological adjustment ($n = 110$)

Variables	Isolation		Minimization		Anger	
	Beta (S.E.)	*p*-value	Beta (S.E.)	*p*-value	Beta (S.E.)	*p*-value
Demographic						
Age	0.029 (0.070)	0.68	0.145 (0.086)	0.095	0.023 (0.090)	0.798
Gender	2.852 (2.233)	0.20	−1.115 (2.804)	0.691	4.254 (2.846)	0.138
Marital status	1.672 (2.555)	0.95	−5.845 (3.140)	0.065	4.779 (3.241)	0.143
Disease						
Metastatic site	−1.299 (0.904)	0.15	0.115 (1.142)	0.919	0.035 (1.169)	0.976
Time since first metastases	−0.004 (0.004)	0.32	0.006 (0.005)	0.233	−0.009 (0.005)	0.075
Treatment	0.582 (1.731)	0.74	−3.035 (1.992)	0.130	1.321 (2.263)	0.560
QOL indicators						
Feeling sick	−0.135 (0.032)	<0.001	0.117 (0.039)	0.003	−0.145 (0.043)	0.001
Tiredness	−0.159 (0.030)	<0.001	0.190 (0.035)	<0.001	−0.251 (0.037)	<0.001
Physical well-being	−0.017 (0.007)	0.017	0.023 (0.009)	0.01	−0.026 (0.010)	0.011
Appetite	−0.016 (0.008)	0.05	0.019 (0.009)	0.04	−0.021 (0.010)	0.038
Cognitive appraisal						
Independence	0.249 (0.044)	<0.001	−0.288 (0.053)	<0.001	0.361 (0.055)	<0.001
Family	0.122 (0.033)	<0.001	−0.148 (0.039)	<0.001	0.138 (0.043)	0.002
Disease	0.283 (0.043)	<0.001	−0.311 (0.053)	<0.001	0.373 (0.055)	<0.001
Coping						
Active	−0.055 (0.043)	0.204	−0.095 (0.051)	0.065	0.097 (0.055)	0.081
Distraction	0.060 (0.053)	0.260	0.121 (0.064)	0.061	0.082 (0.068)	0.230
Avoidant	−0.096 (0.056)	0.089	0.025 (0.068)	0.714	0.003 (0.073)	0.967

have better indicators of QOL and low levels of concern about their disease, independence and family.

Psychosocial variables found to be significant in the univariate or 'family' analyses and demographic variables found to be significant in the final multivariate model are shown in Table 4. Males felt more isolated and angry than females. Patients' tiredness and concern about their disease were associated with all three measures of psychological adjustment. That is, feeling tired and having high levels of concerns about their disease was

Table 4. Summary of final model for isolation, minimization and anger (psychological adjustment)

	Isolation		Minimization		Anger	
	Beta (S.E.)	p-value	Beta (S.E.)	p-value	Beta (S.E.)	p-value
Demographic variables						
Gender	4.18 (1.84)	0.025			6.84 (2.22)	0.003
Quality of life indicators						
Tiredness	−0.12 (0.03)	<0.001	0.16 (0.03)	<0.001	−0.17 (0.04)	<0.001
Cognitive appraisal						
Independence					0.16 (0.06)	0.009
Disease	0.25 (0.04)	<0.001	−0.26 (0.005)	<0.001	0.24 (0.06)	<0.001
Coping style						
Active			−0.11 (0.05)	0.012		
Distraction			0.18 (0.06)	0.001		
Avoidant						

associated with feelings of isolation and anger, and with not being able to minimize the impact of the cancer. Those who were able to minimize the impact of their cancer used distraction and low levels of active coping.

The final models for isolation, minimization and anger did not include the fixed time effect. That is, when the effects of the other variables were controlled for, isolation, minimization and anger no longer deteriorated over time. Exploratory analysis revealed that it was the inclusion of tiredness in the model for minimization that reduced the time effect. Furthermore, tiredness increased over time ($t = -0.077/0.022$, $p = 0.001$). Thus, there appears to have been a confounding between change in minimization and change tiredness in this analysis.

DISCUSSION

This study sought to explore the psychological experience of metastatic melanoma patients in the last year of life. It was expected that as death approached, these patients would become more distressed, that they would move from using problem-focused to emotion-focused coping strategies, and that psychological adjustment would deteriorate.

Our findings did not support this model of stress and coping, as advanced by Lazarus and Folkman (1984). First, patients' cognitive appraisal of their situation as reflected by patient concerns did not, on average, change over the last year of life. Patients did not express increasing concerns with respect to their disease, independence, or the impact of the cancer on their families. Overall, only a few patients reported high levels of concern. A minority (16%) of patients did express a high concern about their family, suggesting a need for interventions that target patient-family communication and the support of carers. These results are consistent with the findings of Liang *et al.* (1990).

Contrary to our second hypothesis, patients' use of problem-focused coping increased over the final year whereas the frequency with which patients used emotion-focused coping strategies did not change. Specifically, patients became more likely to actively engage in behaviours such as seeking more information about their situation, talking to friends and family or doing anything that might help. They did not, however, increase their use of distraction (e.g. 'trying to forget, putting it out of my mind') or avoidant (e.g. 'drinking, eating or taking drugs to feel less tense') coping strategies. Perhaps at this time of their illness, patients are shifting their focus from fighting the disease to putting their affairs in order in a timely fashion and making the most of their remaining time. Thus problem-focused coping, while no longer helpful in resolving disease issues may still be important for the terminal patient.

As expected, psychological adjustment deteriorated over the final year of life. That is, on average patients reported increasing levels of stigma/isolation (e.g. 'I try not to let people know about my cancer') and anger (e.g. 'I am

constantly asking myself the question—why me?') and found it increasingly difficult to minimize the impact of the cancer on their daily lives. However, this change did not remain significant in the multivariate models and was linked to increasing levels of tiredness.

Fatigue may have several causes including the disease itself, treatment of the disease, infection, depression or anxiety (Smets *et al*., 1993; Glaus, 1998). Relationships between fatigue, mood and patients' ability to function are not simple, and make it difficult to establish causality. For example, associations between fatigue and mood may be confounded by pain (Coyle *et al*., 1990; Kuuppelomaki and Lauri, 1998; Stone *et al*., 1999) and treatment may exert independent effects on both fatigue and mood (Visser and Smets, 1998). Nevertheless, it appears that patients with terminal illness experience physical and psychological deterioration with many symptoms occurring concurrently (Coyle *et al*., 1990; Vanio and Auvinen, 1996; Aas *et al*., 1997; Kuuppelomaki and Lauri, 1998). Further research is needed to delineate these relationships more precisely so that appropriate interventions can be implemented.

Of the disease and demographic variables, gender was the only variable associated with adjustment, with men feeling on average more isolated and angry than women. This finding emerged only in the multivariate analysis, suggesting complex interactions between gender and other variables. Stanton and Snider (1993) also found a demographic variable (in their case, age) to be associated with adjustment in multivariate, but not univariate analyses. However, further work is needed to untangle these complex associations.

As expected psychological adjustment was also related to patients' cognitive appraisal of their situation. High levels of concern about their disease were associated with feelings of isolation and anger and with not being able to minimize the impact of the cancer. The fact that patients' concerns were associated with adjustment even when physical indicators of QOL were controlled for, implies that patients' concern about their disease or independence, as well as physical discomfort, were important and should be addressed within patient care.

Contrary to expectation, an avoidant coping style was not associated with psychological adjustment in these patients. This result may be interpreted in a number of ways: first, different psychological processes may operate in the final year of life, second, our measures of psychological adjustment may differ from those previously reported (Dunkel-Schetter *et al*., 1992; Carver *et al*., 1993; Stanton and Snider, 1993; McCaul *et al*., 1999).

Nevertheless, our results did show that those patients who were able to minimize the impact of their cancer were more likely to use distraction and less likely to use active coping. This latter result is of particular interest since minimization has been shown to predict survival duration in the same population of metastatic melanoma patients (Butow *et al*., 1999). We are currently evaluating the impact of a psychosocial intervention designed to increase optimism and minimization of the effects of cancer in metastatic cancer patients. Distraction techniques are now being incorporated into this therapy, as a result of these findings.

Several limitations to the study should be noted. First, the participation rate was relatively low, with only 52% of those being invited to join the study, agreeing to do so. It is not possible to determine whether the non-respondents were more avoidant or whether they declined involvement due to the advanced stage of their disease, as they were closer to death at the time of recruitment. This creates some uncertainty about the generalizability of our results. Second, the spacing and timing of questionnaires was such that subtle changes occurring in the period immediately before death may have been missed. This is an important consideration given that only 37% of patients completed questionnaires in the last 2 months of life. Third, it is important to note that the statistical techniques applied here allowed us to examine longitudinal change using relatively few patients (26%) who completed more than two questionnaires. Thus, the data are limited in terms of assessing individual variation in change over time and results should be interpreted with caution. Fourth, while the data were collected longitudinally, the associations between psychological adjustment and the covariates are effectively cross-sectional, and causality cannot be implied. Fifth, men were under-represented in the sample. Sixth, in including only those patients who died within the study period, we may have selected patients whose disease was more aggressive than average. Finally, the internal reliabilities for the variables measuring problem-solving coping (avoidance and distraction) were low. This suggests that the items may not accurately measure

these particular constructs and may have contributed to the non-significant findings associated with these variables. Nevertheless, the sample was homogenous in terms of cancer type and stage and the 110 patients provide reasonable estimates for understanding the differences between patients in terms of their average levels of functioning.

Much research has focused on distress, coping and psychological adjustment at the time of diagnosis and in the period thereafter. In this study we focused on patients psychological adjustment in the last year of life. These findings suggest that while patients work hard to actively cope with their disease, as they move closer to death, they experience increasing levels of tiredness, and deterioration in their mood and ability to function in their daily lives.

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